
Public empowerment through accessible health information*

By Margaret Calvano, M.S., M.S.I.S., AHIP †
Director, Health Information Programs

Reference Point Foundation
7135 Minstrel Way
Suite 204
Columbia, Maryland 21045

George Needham, M.L.S.
Executive Director

Public Library Association
American Library Association
50 East Huron Street
Chicago, Illinois 60611-2795

The Public Library Association (PLA) is developing plans for cooperative consumer health information services. Foremost for developing this program is the need for partnerships with health agencies and mechanisms to attract grant funding. The proposed project will expand the role of public librarians to address the health information queries they receive effectively. The project plans include the use of new technologies for delivery of health information, and the provision of tools, training, and resources.

ORGANIZATIONAL COOPERATION TO ENHANCE PUBLIC ACCESSIBILITY TO HEALTH INFORMATION

Information providers, including public libraries, health sciences libraries, the government, and nonprofit organizations, are faced with a burgeoning demand for useful consumer health information. A growing awareness among nonprofit health agencies that they can no longer function as islands in a sea of information has led to collaboration in providing information services. Ushered in by an era of expanded alliance-building among visionary organizations and libraries, a concerted effort is being launched to advance computer-aided access to consumer health information.

The Public Library Association (PLA) is leading the way with exploratory research, the development of effective training tools for public librarians, and the creation of partnerships with agency producers and disseminators of health information. The PLA is

working with the Reference Point Foundation's Information Exchange, which was established in 1994 to develop a powerful electronic utility for nonprofit and government health agency information producers, and to serve as a centralized agency for the creation of effective organizational alliances.

NEW TECHNOLOGIES FOR DELIVERING CONSUMER HEALTH INFORMATION

Over the past two years, the PLA has been involved in several initiatives in technology and health information. A *Checklist for Connecting Public Libraries to the Internet* [1], published by the association in 1995, provides library directors, management, and trustees with an overview of the policy decisions and connection options they will encounter as they make the decision to go online.

In addition, the PLA is preparing a report on a study of public libraries and health information dissemination. Sponsored by the Robert Wood Johnson Foundation, the study looked at the background of public libraries and health information, reviewed the successes and failures of several currently operating consumer health information networks, and proposed options for the future. Several factors that are

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† Currently senior director of library and information services, Epilepsy Foundation of America, 4351 Garden City Drive, Landover, Maryland 20785.

key to the creation of a successful health information project were identified.

Planning

The librarian has to know what is happening in the community before proceeding. What is the local literacy level and the overall educational attainment of citizens? What are the age, racial, and other demographic characteristics of the community? What are the major industries and other economic factors? The answers to all these questions will affect the type of information and formats that should be offered.

Cooperation

Public librarians are encouraged to create alliances with hospital librarians, medical school librarians, local health professional societies, clinics, public health offices, high school health sciences curriculum developers, and any other identifiable stakeholders in the community. To promote alliance building, an article was published recently about a librarian in a small city in Utah who totally revised the library's medical collection and the effectiveness of the delivery of this information through intensive involvement with the local health care community [2]. Such involvement helps to ensure several things. First, it helps to guarantee that persons who are the most knowledgeable about the community's health contribute to the collection-development process. Second, it creates a sense of ownership and trust in the collection among the health care professionals who will be referring their patients to the library. Third, it creates goodwill in the health care community toward the library in all its endeavors.

Guaranteed availability of information

To guarantee availability of information, the Department of Health and Human Services (DHHS) Office of Disease Prevention and Health Promotion plans to create a centralized online clearinghouse of health information produced and disseminated by federal agencies across departmental lines. The Reference Point Foundation is also developing a system that will provide similar accessibility to the materials of voluntary, nongovernmental health organizations.

Provision of tools and know-how

The PLA is working with the American Library Association's Fund for America's Libraries and the Robert Wood Johnson Foundation to obtain a National Telecommunications and Information Administration (NTIA) grant. The grant monies would enable the PLA to equip public librarians with computer systems technology, specifically to allow them to create effective health information networks. A major

component of the project would be staff training, which is such a vital element, but is all too frequently overlooked. Appropriate tools that librarians and their clients can use immediately and effectively must be introduced.

Finally, an uncomfortable topic arises: reexamination of the librarian's role. One of the basic tenets of reference librarianship has been that the client could be directed to information and material could be presented, but the information could never be interpreted or restated to assist in comprehension. This was especially true in the areas of legal and medical information. However, if librarians, especially public librarians, are going to venture into the dissemination of health information, then this role must be reexamined. A dialog with health care professionals, including practitioners, educators, and individuals in all related fields must be initiated to determine the extent to which public librarians should use their specialized training and the powerful tools at their command to help users comprehend health information. This issue is the final node in the consumer health information network.

Collaboration with nonprofit agencies

Public-private partnerships—a popular term in the 1990s—are a key component in the development of the Information Exchange at the Reference Point Foundation. The Information Exchange is a nonprofit electronic utility designed to make consumer health information widely available to the public, beginning at the public library. This project is being carried out with assistance from sponsoring and collaborating partnerships with private corporations and nonprofit organizations.

A recent survey of the voluntary health agencies that provide public information services pointed to a vast demand for consumer information (see Figure 1). These data reflect clients served by a small cross-section of health agencies. The numbers do not account for the surges that occur when these same agencies receive calls following news stories—a volume of calls that often reaches many thousands each day and sometimes causes even the more sophisticated telecommunications systems to fail.

Such "communications crises" [3] have created a need for a viable consumer health information vehicle such as the Information Exchange—one that disseminates information maintained separately by each health agency, information that is timely and authoritative and carries professional advisory committee approval. Much of the information should be free; however, the public should also be able to order priced items through an interactive system.

A series of focus groups was held by the Information Exchange as part of a DHHS project on con-

Figure 1
Voluntary health agency annual information services statistics

> 100,000 health-related inquiries annually	1,000–50,000 health-related inquiries annually
Alzheimer's Association American Cancer Society American Diabetes Association American Lung Association Arthritis Foundation Epilepsy Foundation of America Lupus Foundation of America March of Dimes Birth Defects Foundation National Multiple Sclerosis Society	Acoustic Neuroma Association National Psoriasis Foundation Sjogren's Syndrome Foundation The Foundation Fighting Blindness

Source: Voluntary Health Agencies Information Services Survey, Reference Point Foundation, 1994.

sumer health information access and delivery. In all these groups, most participants wanted health information to be interpreted by their primary care providers. It was acknowledged unanimously, however, that primary care physicians either have little time for questions and explanations or appear to be unable to communicate technical information effectively to a lay person.

PARTNERSHIPS

The PLA is an important partner as the Information Exchange initiates, on a large scale, the electronic dissemination of consumer health information through public libraries. The demand for health information from public libraries in the United States is prodigious. An estimated 8% to 10% of all reference questions are related to health [4]. On the supply side, the Information Exchange is working with an umbrella group of health agencies, the National Health Council. Of its forty-three voluntary health agency members, twenty-five have formed a health information alliance and are committed to the Information Exchange as charter members.

In addition, agencies of the federal government, including the Centers for Disease Control and Prevention (CDC), are working with the Information Exchange during the development phase. Other federal agencies have expressed interest and will make their information, much of which is free, available in electronic form.

The platform for the Information Exchange is located at the Online Computer Library Center (OCLC), another nonprofit partner. Information will be accessible through OCLC's First Search, as well as through the World Wide Web. All medical library, hospital, and clinic information services that are con-

nected to either of these resources will also have access to the Information Exchange.

On the private side, development partners have included the Sprint Corporation, with the participation of Electronic Data Services. Other private funding and development partnerships are being cultivated.

The goal of the Information Exchange is to help empower the public by providing accessible, comprehensive, and understandable information. A prototype of the system, containing information from the Arthritis Foundation and the CDC, was demonstrated on May 14, 1995, at the DHHS conference, Partnerships for Networked Health Information for the Public.

AN EXPANDED ROLE FOR LIBRARIANS?

An understanding of factors related to personal health is a critical basis for making appropriate health care decisions. The current climate in medical care has shifted the responsibility for many health care decisions to the patient, while at the same time providing little basis upon which these decisions can knowledgeably be made [5].

For some, however, information alone will not be enough. There is a need for the translation of medical jargon into common English—a restatement of the written word, so that the general public can comprehend the information and convert it into knowledge. The question is Who will the health information intermediaries be? Is there a new profession, discipline, or subspecialty on the horizon? Should comprehensive, understandable information be provided on a reimbursable basis, as has been suggested [6]?

The issue of how best to clarify consumer health information should be addressed by a number of health professional groups, including health sciences librarians. The librarian, after all, collects and disseminates much of the information sought by the consumer. During these times of change in health care delivery, it is important to help the public understand information relevant to their own or their loved ones' personal health. To that end, an intermediary who is able and willing to translate information will often be needed. Through this partnering effort, perhaps the public can be empowered by the increasing amounts of health information they are able to access.

Finally, the public library, which 122 million people visit each year, will soon be equipped with the technology that will encourage the public's use of electronic resources in health information. Health professionals must be prepared to educate, so that the public can independently understand and evaluate the mass of information that will be disseminated electronically.

CONCLUSIONS

Demand for consumer health information has grown considerably over the last decade, and a large group of nonprofit and government health agencies is considering how best to meet consumer needs. The PLA, recognizing the importance of consumer health information, has assumed a leadership role. All these organizations are working together to find ways to make high-quality, authoritative consumer health information available to all through the use of new technologies and access through public libraries.

Health care innovations such as physician-patient partnerships, which require patients to carry the responsibility for personal health care decisions, bring with them the need for knowledgeable patients. Now that rapidly developing information technologies offer a means for information dissemination on a broad scale, the time is right for a collaborative effort among health agencies to use a nonprofit electronic utility such as the Information Exchange to make the requisite information widely available through a centralized, user-friendly, and well-organized electronic resource.

One issue that needs to be addressed is that of the learned health information intermediary. Without assistance from such an intermediary, no amount of quality health information, even when easily accessible, will help consumers with personal health care.

By providing well-written, easily comprehensible health information, and the interpretation or restatement of that which is hard to understand, librarians and other information professionals can have a genuinely positive effect on the public's health.

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